



A BY US FOR US GUIDE

Isolation and Enhancing Social Connections

An inspirational guide for people living
with dementia and care partners

SERIES 2

Introduction

Keeping socially connected with friends, family and your community can help you live well with dementia and improve your physical, mental and emotional wellbeing. Social connection is the experience of feeling close, loved and valued by other people. A lack of quality relationships and feelings of belonging may lead to feelings of loneliness.

Loneliness is an unpleasant emotional response, often including feelings of sadness, depression and stress, resulting in overall negative health consequences. It is possible that you could feel lonely even if you live, work or socialize with others. Social isolation is defined by the total number of social connections a person has. Whether someone feels socially connected to others depends on the quality of their connections and not necessarily the quantity of them. Regardless, for many people, it is important to continue to find ways to take part in a variety of activities to help stay connected to others and reduce your risk of loneliness.

Dementia can change how a person connects with others and their community, meaning people living with dementia and their care partners are at a higher risk of social isolation. For some individuals living with dementia, their social habits and preferences remain the same, whereas others may become apathetic, lacking interest in socializing or participating in activities with others. Being apathetic may not mean these individuals are socially isolated and they should not be pushed to connect with others. This guide outlines how people living with dementia and their care partners might experience social isolation and offers some strategies to help you reduce your risk for social isolation and enhance your social connections.

Risks factors for social isolation

In addition to living with a dementia diagnosis, there are other factors that may increase your risk for social isolation such as being a part of a marginalized community, age, health, living situation, finances or stigma.

Marginalized communities

People from marginalized communities may be at risk for social isolation due to fear of discrimination or lack of social recognition. Some examples of these communities are:

- Indigenous peoples
- People living with mental health conditions
- People living with disabilities
- Ethnic or cultural minorities
- Lesbian, gay, bisexual, transgender, queer and/or Two-Spirit (LGBTQ2+) community

Age and health

Age and health challenges can increase a person's risk for social isolation in the following ways, especially during flu outbreaks:

- Growing older can result in having less family and friends to connect with.
- Existing medical conditions and complications may make people more vulnerable, restricting their ability to socialize in-person.

Risks factors for social isolation continued

- Needing to wear masks may result in troubles communicating such as difficulty hearing someone speak and not being able to see who people are. People living with dementia may also have to be reminded about the need to wear a mask.
- Rules and instructions about how to stay safe during flu outbreaks may not be clear and may change frequently causing confusion.

Living situation

- Living alone.
- Living in a group setting such as a long-term care home and not being able to leave your home to socialize and engage in activities during times of flu outbreaks.
- Living in a rural area with a small population and limited services.
- Needing to stay at home during a flu outbreak and not being able to participate in usual social activities with family and friends.
- Not having access to transportation.

“After 57 years of marriage, it became necessary for my partner to move into a care home due to his advancing dementia. It was the first time in my entire life that I ever lived alone. This was a huge adjustment for me, coping with the separation, adapting to being on my own and the increase in financial burden.”

(Anne Hopewell, Care partner)

Risks factors for social isolation continued

Finances

Finances are often affected when you are living with dementia. You may have to stop working and rely on a pension or disability benefits as income. You may still have a lot of financial responsibilities such as a mortgage, children to support or debt. Some transportation options may have a cost, limiting ability to participate.

If your partner moves into long-term care, you may be entitled to financial benefits. This is called involuntary separation. Contact your local government agencies for more information.

Stigma

Stigma associated with dementia includes negative attitudes, preconceived ideas or discrimination against a person because they have dementia or are caring for a person living with dementia.

- You may feel a lack of acceptance, understanding, respect, or that you are being treated differently.
- You may be told that ‘you don’t look like you have dementia’ or that you are lying about what you are experiencing. This is hurtful and can cause feelings of isolation.
- You may feel embarrassed, ashamed or fearful. This is hurtful and can cause a person to isolate themselves.

Risks factors for social isolation continued

Coping tips and strategies

- ✓ If someone tells you “you don’t look like you have dementia”, ask them **what dementia looks like**.
- ✓ Share your knowledge and experience with others to educate them about what it is like to live with dementia. This increases awareness of the fact that people living with dementia can still engage in activities.

What others can do

- ✓ Learn about dementia and what a person living with dementia and/or their care partners might be experiencing.
- ✓ **See the person, not their dementia.**

“There is a stigma about [living with dementia]. It is hurtful, harmful. It creates loneliness and, it keeps me from participating in a multitude of different things ... It [is] all about participation, being accepted.”

(Person living with dementia)

Changing abilities



Changing abilities and other changes associated with dementia may make it more difficult to socialize and can create feelings of being isolated.

Being tired

Being tired or getting tired quickly can affect all aspects of your life including being social. You might be invited to dinner or another event, but feel too tired to go at that time. You may fear that if you decline invitations, your family or friends will stop including you.

“Dementia causes an increase in tiredness, which has an effect on your ability to socialize. For example, there may be an event, and you have to go home early because you are tired. You may not get to go at all because it’s too far away and the dementia causes you to be unable to drive.”

(John Hammel, Person living with dementia)

Changing abilities continued

Coping tips and strategies

- ✓ Put yourself first and try to develop a routine. Although it may be difficult to say 'no' to family and friends, if you are not feeling comfortable socializing - it is ok not to accept invitations to events.
- ✓ Let people know that you still want to be invited to events. When you receive an invitation, tell them you may not be able to confirm your attendance ahead of time or you may need to cancel last minute.
- ✓ Invite people to visit you instead of visiting them.
 - If needed, make sure you have a quiet space to be alone in your home.
- ✓ Plan ahead before attending an event or activity.
 - Consider the time of day and where the activity is happening. Go to events early when it may be less busy.
 - Before the activity, take some time to rest with your eyes closed or find a quiet space during the event to rest if needed.
 - When possible, keep groups small. This will help to reduce noise, stimulation and the number of conversations.
 - Focus on your strengths and abilities in the moment.

Changing abilities continued



Sensory changes

Sensory changes may make it difficult to enjoy social activities.

- You may no longer be able to cope when too many things are happening at once.
- You may be fearful or anxious about being in large crowds. You may find it hard to hear or be more sensitive to loud noises.
- You may experience changes in depth perception, hallucinations or other vision changes.

Changing abilities continued

Coping tips and strategies

To reduce noise, echoes and distractions if you have trouble hearing or find it too loud at a social event or activity:

- ✓ Ask the person you are speaking with to talk slower.
- ✓ Sit with your back against the wall, in a corner, in a booth or at the end of a table.
- ✓ Search for restaurants in your area that do not play music, or ask for the music to be lowered.
- ✓ Wear ear plugs/buds or clothing with a hood or a hat to cover your ears.
- ✓ Listen to music or a white noise app on a device to reduce background sounds.
- ✓ Schedule yearly hearing tests.

If you are experiencing vision changes and hallucinations:

- ✓ Check with your pharmacist or physician to see if your medication may be causing these changes and if you can adjust it.
- ✓ Check if events are accessible and can accommodate your needs. Avoid dark area rugs or other tripping hazards, and check for good lighting, clear signage and a quiet place to get away from stimuli.
- ✓ Schedule regular eye examinations.

Changing abilities continued

Your care partner may be able to remind you of what you need to do in social situations in order to feel comfortable. For example, letting you know that you prefer a certain restaurant because it is quiet. Reminders can be your new best friend.

What others can do

- ✓ Let the person living with dementia or care partner know when an event is happening and give them a choice about whether to attend.
- ✓ Understand that a person with dementia may experience changing abilities and sensory changes that make it difficult for them to attend social activities.
- ✓ Be compassionate if a person living with dementia or care partner tells you they cannot confirm their attendance at an event or if they have to cancel at the last minute.
- ✓ Accommodate and be open to socializing according to the person living with dementia's/care partner's schedule and ask them what support they need to feel more comfortable socializing.
- ✓ If the person living with dementia is not comfortable interacting in person, provide other options such as a telephone call or video chat.
- ✓ Realize that a person living with dementia may need help one day even though they didn't need it the day before – needs can change on a daily basis.

Communication challenges

Communication challenges may make it more difficult for you to socialize with others.

- You may find it difficult to follow conversations.
- You may experience changes in speech and language such as trouble finding the right words.
- You may find it confusing to use a phone or other devices.

When a person living with dementia experiences changes in speech and language, people may not know how to talk to them. Sometimes these changes lead people to talk to the care partner rather than the person living with dementia. This leaves the person living with dementia feeling left out of the conversation. Dementia can also change the conversation topics. Friends and family may focus on asking questions about dementia, rather than the things they used to talk about.

Coping tips and strategies

- ✓ Tell people that you have dementia and that you need more time to process what they are saying.
- ✓ When talking to someone, if you are unsure if you have heard them correctly, repeat what you heard back to them to confirm what you have understood.

What others can do

- ✓ Speak directly to the person living with dementia and give them opportunities to join the conversation. Keep questions short and don't give too many options. Pause to give them more time to process what is being said and to think about their answers.
- ✓ Learn how to communicate with someone who has challenges communicating. Pay attention to non-verbal cues and body language.



For more tips for communicating with people living with dementia, refer to the By Us For Us guide: **Enhancing Communication**.

“You were expecting conversations to continue on as they had in the past. And they didn’t really do that. They kind of came to an abrupt stop. More concentration was put . . . on what you were going through rather than what you wanted to do socially.”

(Person living with dementia)

“Friends and family don’t feel comfortable around my husband. [They] don’t know what to say or [how to] act around him. Therefore, invitations for social or family gatherings stopped.”

(Care partner)

Changing abilities continued



Changes in mobility

People living with dementia who experience mobility, balance, spatial or orientation challenges may find it more difficult to engage in social activities. They may have to stop driving and care partners may no longer get to experience the 'fun' of being a passenger in a car. Transportation to events or attending appointments may be challenging if the care partner is not able to drive.

Changing abilities continued

Coping tips and strategies

- ✓ Use mobility devices such as a walker or cane to assist with mobility.
- ✓ Check if events are accessible and can accommodate your needs.
- ✓ If needed, ask someone to assist you to attend social activities.
- ✓ Check your community transportation options. Check with your local transit service provider to see if they offer reduced fares for care partners or if there is accessible transit.



For more information on the driver's license process and other safety tips, refer to the By Us For Us guide: **Living Safely** and **Safety When Out and About**.

“... the department of transport put a letter in my mail box telling me they were taking my drivers' license ... And I was in ... shock. Something I have been able to do for so many years, since I was 14 ... but because I have dementia, my doctor wrote a letter to the department of transport and they took my license away.”

(Person living with dementia)

Changing abilities continued

Challenges with engaging in activities

Living with dementia may affect your motivation to take part in social activities.

- You may feel that you need to stop taking part in group activities due to feeling lost and not being able to focus.
- It may be challenging for you to begin an activity on your own or start conversations.

Coping tips and strategies

- ✓ Try activities in pairs instead of groups.
- ✓ When attending an activity, position yourself in an area where you feel most comfortable.
- ✓ Choose a limited number of fun activities to do, so you don't risk becoming overwhelmed by too many choices. If an activity is challenging, causes discomfort, or makes you too tired, try a different activity.

Changing abilities continued

Caring for a person living with dementia may affect your motivation and ability to take part in social activities.

- You may feel frustrated, tired or exhausted or like you no longer have your own identity.
- Even though you may want to get involved in groups or find support, you may not feel motivated to do the work to find them.
- It may be difficult to go out alone and socialize when you used to do this with your partner.

Coping tips and strategies

- ✓ Schedule some time alone. Don't put yourself last – arrange for support for the person living with dementia so that you can engage in social activities on your own.
- ✓ Reach out to others who understand what you are going through. Ask your local Alzheimer Society or other community organizations if they offer in person or online support groups.
- ✓ It is important to join social activities that are not dementia related and have friends outside the 'dementia circle'. It is ok to take a break from caring and talk about topics other than dementia. Don't feel guilty about this.
- ✓ Identify what self-care means to you. It is important to recognize what you need and how to take care of yourself.

Changing abilities continued

Coping tips and strategies

- ✓ Write down your feelings and emotions in a journal.
- ✓ Accept help when it is offered to you.

What others can do

- ✓ Offer to cook meals.
- ✓ Assist the person living with dementia to engage in activities.
- ✓ Spend time with the person living with dementia to give the care partner time to engage in other activities.

“He used to be active and initiate social contact and his own activity. He no longer drives, seems unable to deal with the phone, is often confused about daily life, [and] does not reach out to others. Finances, household tasks, meal preparation, health, and his recreation are now all on my plate.”

(Care partner)

“For me, I kayak a lot for my respite, because I find as our roles change and I take on more, that sometimes I feel claustrophobic and a little panicky myself. I need the space to get a grip, so I kayak. I love having alone time to myself.”

(Care partner)

Changes to employment

People living with dementia and care partners who work may find it difficult to remain socially engaged. For those who leave the workforce, this may also impact social connections as well as finances.

Coping tips and strategies

- ✓ Ask your employer if they can make accommodations:
 - Have another person check your work so they can help you identify what tasks you might need to handover.
 - Check if you can work part-time or flexible hours.
- ✓ If you prefer to be busy, try to do so, but realize that you may have to slow down in the future.
- ✓ Look into disability benefit options.
- ✓ Find a new purpose or volunteer at an organization that will understand your needs as a person living with dementia or care partner.

“For me, realizing that I didn’t get up and go to work every morning. I didn’t have all those responsibilities. Really the most difficult [part] for me through that transition [was] feeling that isolation from everybody.

(Person living with dementia)

Changes in relationships



Friends and family

Living with dementia or caring for a person living with dementia may affect relationships with your family and friends.

- They may find it difficult to see you experience changes and may not know how to interact as well as they used to.
- They may no longer feel comfortable visiting or may stop inviting you to social activities, making you feel left out.
- It may be difficult for you to visit them if they live far away.

Changes in relationships continued

Coping tips and strategies

- ✓ Keep in touch with friends and family. Use the phone or try a video call. If you live alone, ask a care partner to check on you.
- ✓ Encourage them to join a support group or attend education sessions to learn more about dementia. This may help with acceptance and help them learn how to better communicate and engage with people living with dementia.
- ✓ If you are speaking at an event about your experience living with dementia or caring for a person living with dementia - invite them to hear you speak.
- ✓ Create videos or write stories about your experience and share them so they can learn more.
- ✓ Ask them if there is anything they want to ask you and tell them it is ok to ask. This gets the conversation started and helps to reduce the stigma.

“... people kind of shy away from you a bit once you get the diagnosis of dementia, because they don’t know how to react to you ... [as before].”

(Person living with dementia)

Changes in relationships continued

Dementia may also affect the relationship between a care partner and their life partner.

- Intimacy between you and your partner may be affected due to the changes that are occurring. It may not feel like the same relationship it once was.
- You may start to feel more like a care partner than a life partner.
- You may experience increased isolation if your partner moves to long-term care or passes away and you live alone.

Coping tips and strategies

- ✓ Learn from others with similar experiences - read books, watch videos or research online.
- ✓ Try to increase your social circle - meet new people.
- ✓ Seek out counselling from a social worker or a spiritual advisor.
- ✓ Have open, sincere and honest conversations with your partner about what you are feeling and experiencing.

Changes in relationships continued

What others can do

- ✓ Understand that there is a negative stigma associated with dementia and intimacy. Some people living with dementia may have challenges with judging the appropriateness of sexual expressions, and some may not. People living with dementia should still be given opportunities to express their need for closeness and intimacy.



For more suggestions on how to adapt to changing relationships, refer to the By Us For Us guide: **Role, Health and Wellbeing**.

“I feel socially isolated because I see him becoming more withdrawn and dependent. I am uncertain about how long I can be away and if meeting my needs mean[s] I am neglecting him.”

(Care partner)

“At the end of the day, I do a lot of volunteering...It was just a way you are getting involved with other people and it gives you something to look forward to.”

(Care partner)

Staying connected



In order to stay socially connected, it is important to have a social network of people you can trust. To enhance your social connections, try to engage in activities such as those listed below either in person or virtually (online).

- Hobbies: photography, painting, woodworking, pottery, puzzles, cards and games, crafts, colouring, genealogy research, reading, listening to music, gardening, bird watching, theatre, traveling, volunteering, making or watching videos.

Staying connected continued

- Recreation: exercising, biking, walking, dancing, participating in or watching sports.
- Spending time with family, friends and pets: having coffee or meals, shopping, joining a social group, talking on the phone, texting, email, video chat, or online forums.
- Religious and spiritual activities.
- Day programs, community activities, support groups; attending webinars and education about dementia or attending classes; participating in research studies and projects.

Ask your health care provider(s) if they can refer you to any social activities or services (social prescribing).

“I have figured out how to incorporate doing hobbies, [such as] woodworking, photography and painting. Simple little jobs that are only two or three steps that my brain can handle ... By doing this, I’ve been able to decrease social isolation.”

- John Hammel, Person living with dementia

“As a life partner to someone that was diagnosed with young onset dementia at the age of 45, I have had to start to carve out a new life for myself including utilizing social media to reconnect with old friends and make new ones.”

(Dawn Baxter, Care partner)

Community services

Check for services and activities that may be available in your community.

- Alzheimer Society (social workers, groups, education and events).
- Community services (home care, volunteer friendly visiting, meals, shopping, housekeeping, exercise programs, day program and medication alerts).
- Government programs.
- Legions and Rotary groups etc.
- Libraries.
- Places of worship.
- Community or seniors' centres.
- Respite (short term care for people living with dementia).
- Family and Resident Councils in long-term care.

“It’s good to have the day program. It’s just wonderful. It’s the best place for me to be if I don’t have anything else to do, I really enjoy it.”

(Person living with dementia)

“My husband arranges one on one coffee visits in person and virtual[ly] for me. My tablet allows me to visit virtually with friends.”

(Person living with dementia)

Personal development

- Be proactive! Reach out to friends and family. Find ways to get involved in activities.
- ‘Put yourself out there.’ Find ways to make new friends – this might be a different from how you made friends before.
- Don’t always rely on others. Advocate for yourself. Speak up!
- Find time to do things on your own. It can be helpful to be become more comfortable with yourself.



For more suggestions on how to stay connected, refer to the By Us For Us guide: **Living and Celebrating Life Through Leisure.**

“I’m proactive enough to keep my wellbeing in good shape. I’ve accepted my situation and I’ve moved on.”

(Person living with dementia)

“I know that if I don’t stay on a one-to-one basis with a number of people, I’m losing a relationship with them... I have to work at reaching out to other people and say[ing] can we do this? ...I at least have some awareness of what’s available to me.”

(Person living with dementia)

Resources

Alzheimer Society of Canada: Toll-free telephone: 1-800-616-8816, Email: info@alzheimer.ca, Website: www.alzheimer.ca

World Health Organization: Website: www.who.int

We also suggest that you check for other local, national and international resources.

Endorsements

These guides are the best information possible for somebody with dementia to read.

Dave Van De Cappelle

Person living with dementia

Thank you for this “By Us for Us” guide, which not only supports self-advocacy but also enhances educators’ knowledge of the lived-experience perspective. The guide provides tangential coping tips and strategies to prevent isolation and enhance social connection. It is a valuable tool to assist with supporting care partners and persons living with dementia to make achievable changes to maximize living well.

Dawn Robinson

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Thank you to the working group for preparing this ‘By Us for Us’ guide about social isolation and connections. The guide provides excellent tips and strategies that can be used by persons living with dementia and their family and friends to enhance the quality of their social interactions. Feeling cared about and that we belong always matters. The guide outlines the difficulties faced by people living with dementia and their care partners related to social isolation. Highlighting this problem helps to address the negative impacts that stigma can have on people living with dementia and their care partners. The guide shows us that there are many ways to continue to connect with others, and can inspire each of us, at all stages of our lives.

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Front cover concept

My husband was diagnosed with Frontotemporal Dementia at 47 years of age. He was a very social person but as people realized that he was not his usual self they drew away. He then extracted himself from groups and would stand in a corner on his own. The drawing is depicting a person sitting on their own with a crevice dividing them from the group.

- Vicky Willis, whose husband lived with Frontotemporal Dementia

References

Canadian Mental Health Association. (2020, April 30). Social connection is the cure. <https://mentalhealthweek.ca/social-connection-is-the-cure/>

The National Seniors Council. (2017). Who's at Risk and What Can Be Done About It? <https://www.canada.ca/en/national-seniors-council/programs/publications-reports/2017/review-social-isolation-seniors.html>

About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:
www.the-ria.ca

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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